

Rhode Island Disability Law Center, Inc.

275 Westminster Street, Suite 401, Providence, RI 02903-3434 « The Designated Protection and Advocacy System for Rhode Island »

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By e-mail: RhodeIsland1115Waiver@ohhs.ri.gov February 28, 2013

Rhode Island Medicaid 1115 Waiver Extension Request 74 West Road Building 74 Cranston, RI 02920

Re: Comments on the Medicaid 1115 Waiver Extension Request

Dear Sir/Madam:

On behalf of the Rhode Island Disability Law Center, Inc. (RIDLC) I am submitting the following comments regarding Rhode Island's request for an extension of its 1115 Waiver (formerly "the Global Waiver"). RIDLC is the federally funded non-profit law office designated as Rhode Island's protection and advocacy agency for individuals with disabilities in Rhode Island. Through participation on the legislatively created Global Waiver Task Force and in stakeholder workgroups for Rhode Island's Integrated Care Initiatives, we have been following the state's plans for Medicaid delivery system reforms.

We support the state's goal of removing the federal funding cap and relying instead a more traditional budget neutrality arrangement in this application, and also support the state's efforts to continue previously approved CNOM expenditures. We appreciate the state's recognition that an effective health care system needs a broader definition of health and that social determinants play a large role in health outcomes. Similarly, we appreciate the state's recognition of the need for increased effort to help consumers understand the variety of services and eligibility criteria across state agency programs. Individuals with disabilities in Rhode Island need access to a broader array of housing and employment supports to ensure their health, and to enable their integration and access to a meaningful life. EOHHS' plans to coordinate services across providers and systems will be a key component of ensuring these outcomes. Our more specific comments about the proposal follow.

Ensuring consumer responsiveness and involvement

On page 5 of the request, the state acknowledges the value of "person-centered planning" on improving the effectiveness of managed care. We believe the state should define more specifically the meaning of person-centered care, so it is clear that the

consumer's priorities are recognized. As the state moves towards incorporating long-term care services into managed care, it becomes even more critical that consumers direct the goals of long-term care services and supports, and be fully informed about choices available to them. The establishment of a Consumer Assistance Program within EOHHS will assist significantly in making sure that consumers have access to needed information about all services from EOHHS agencies. We believe that "options counseling" should be made available to consumers from an external source.

The request incorporates the use of a variety of peer services ("peer navigators" "peer specialists" and "peer supports") to help consumers navigate services and access services. We support the *voluntary* use of peer services for consumers, and believe that in order to qualify as a "peer" an individual should have personal experience with the particular service system at issue.

The state needs to utilize multiple means of engaging consumers who are beneficiaries in providing feedback regarding the quality and scope of services. The Global Waiver Task Force has few members who qualify as consumers, and it is not clear that the state has any other formalized means of obtaining feedback directly from consumers. Focus groups and other kinds of targeted meetings with consumers are more likely to result in feedback from consumers than formal public comment opportunities. We urge the state to incorporate these other methods of obtaining consumer feedback on the quality and adequacy of services.

Expanding the continuum of community-based living arrangements

Rhode Island has an array of living arrangements available to individuals needing long-term care services, but there are gaps and capacity issues within that array. For individuals with behavioral health needs in particular, we believe that there are insufficient community-based housing options available in Rhode Island. We support the state's proposed implementation of "community-based services/supportive housing" to expand the options available to consumers to live in their own homes. Under this model, we believe peer supports can be effectively used to support housing stability and engagement in services and community activities.

In implementing this and other models of residential support, we urge the state to establish policies that ensure that consumers are able to live in the most integrated settings appropriate to their needs and that consumers living in the community have a property interest (e.g. ownership, tenancy) in the home in which they are living.

Supporting the employment goals of consumers

In building capacity to provide information to consumers about the array of services available within EOHHS agencies, we urge the state to ensure that its policies regarding employment supports for consumers with disabilities are consistent and complementary, and take advantage of the full range of federal options. We ask that the state revise its supported employment definition on page 62 to conform to the CMS

revised core service definition. See http://www.cms.gov/CMCSBulletins/downloads/CIB-9-16-11.pdf. This definition helps to promote competitive and integrated employment for people with disabilities, as well as for older adults.

We found only one reference to the Working Adults with Disabilities Program -within the list of optional categorically needy coverage groups on page 12. This reference seems to imply that only individuals without third party insurance would be covered. We ask for clarification of this, as well as the state's plans for enrolling working adults into employer plans, as authorized in state law.

Monitoring quality and outcomes

We participated in two time-limited workgroups reviewing long-term care quality measures: the Global Waiver Task Force Quality and Evaluation workgroup; and the Integrated Care Workgroup on Oversight and Evaluation. We appreciate the difficulty in finding standards for assessing long-term care outcomes that are applicable across populations, but encourage the state to utilize and/or adapt those that have been used for specific populations, e.g., the National Core Indicators program for individuals with developmental disabilities (http://www.hsri.org/project/national-coreindicators/overview) the Recovery Measures developed by the Mental Health Center of Denver for behavioral health populations (http://mhcd.org/resource-library/reachingrecovery/recovery-measures) and the Personal Experience Outcomes Interview and Evaluation System "PEONIES" the system used by Wisconsin's Medicaid funded longterm care program for elders and people with disabilities (http://www.chsra.wisc.edu/chsra/projects/peonies.htm). Unlike the CAHPS and HEDIS measures, these assessments incorporate self ratings of community involvement, community integration and other social issues that are more in line with the goals of long term care.

As mentioned previously, we think that consumers should be actively involved in developing and monitoring the outcomes of services, especially long-term care services. We urge the state to use more specific measures to engage consumers in this task, and to require managed care entities to do so as well.

Thank you for the opportunity to comments on this extension request.

Sincerely,

Anne M. Mulready
Supervising Attorney